Engaging Families in Life Course Intervention Research: An Essential Step in Advancing Equity

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abstract

Life course intervention research requires a thorough understanding of complex factors that interact to affect health over time. Partnerships with families and communities are critical to understanding these interconnections and identifying effective interventions. Here, family and community engagement are presented, aligned with the 5 phases of the life course intervention research framework: planning, design, implementation, evaluation, and translation. During planning, the researcher considers their own starting position and what they need to learn from families and the community. The design phase produces a plan for family engagement that is layered, iterative, and includes qualitative methods that will inform life course modeling and the research process. The implementation phase includes administrative actions such as creating opportunities for contributions and providing compensation to family and community partners. The evaluation phase requires measurement of the quality of partnerships with families and community and includes making adjustments as indicated to improve these partnerships. This phase also calls for reflection on the impact these partnerships had on the intervention, including if they made a difference for those being served. During translation, the researcher works with all partners, including families and communities, about follow up steps toward project continuation, replication, or completion. The researcher also works collaboratively in determining how the study results are shared. A holistic approach to health over the life course that is designed and executed in partnership with families and their community can generate research findings with broad practical applicability and strong translational potential.

SUPPLEMENT ARTICLE

Families should play a meaningful role in life course intervention research (LCIR), with an explicit goal of achieving equity.[1] Too often interventions that have been studied without authentic family engagement, and without a goal of equity, are less likely to be effective when applied to groups other than the initial research population or fall far short of addressing the larger problem they seek to solve. Many researchers struggle with engaging families and addressing health equity in their work. What often is not understood by researchers is that these 2 challenges are interconnected. In other words, to achieve equity, researchers must engage the very families that they are seeking to assist. These communities are the experts on their needs and what works for them. While many researchers are beginning to understand this precondition, they struggle with how to do it in an authentic and impactful way. Meanwhile, families and organizations who are interested in research face significant barriers to finding research partners; Table 1 presents some strategies for overcoming these. To ground research in equity, it is important to understand what equity is, how family and community engagement is tied to equity, and equitable strategies for engaging communities and families.

Equity is arguably one of the most important aspects of life course research. As evidenced by disparities in outcomes in health and well-being for children and families who have been minoritized in the United States, researchers must approach their work with antiracist, equity-seeking methods to achieve the outcomes they desire for all people.[1] As such, building the capacity to work in partnership with communities and their representative members is essential. The Life Course Intervention Research Network (LCIRN) recently developed competencies that recommend that family-professional partnership, cultural competency, communication, working with communities and systems, and interdisciplinary team building are incorporated in all levels of research.[2]

The World Health Organization defines equity as the "absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically."[3] Health equity is when individuals, families, and communities have equal access and opportunity to achieve optimal health outcomes, regardless of social, economic, demographic, or geographic difference. Striving for equity is a necessary step toward eliminating disparities and improving health outcomes. Efforts that only focus on equality may ensure that everyone gets the same amount of a commodity but fail to repair inequities at the societal level because this approach does not consider that some groups may need more or different support than others to reach their optimal outcomes in life. Equitable policies,

TABLE 1 Strategies for Community Members Seeking to Connect With Research Partnerships

Strategy	Description
Start local	Find out whether any of the universities or hospitals nearest to you have central offices of community engagement and if so, contact those offices to ask what opportunities might be available for you.
	Browse university websites to find departments, faculty, or special projects that are doing work you might be able to help with.
	For community-based organizations: Work with university departments to offer jobs or internships for graduate students to help you gather and publish data on your own projects.
Network around a particular topic	Join local or virtual conferences that cover your topic so you can attend presentations related to your research interests.
	Connect with a librarian at the university library most convenient for you for help finding out who is already doing research on your topic.
	Find the e-mail address of the corresponding author on academic articles related to your topic and reach out to them.
Take part when you see related opportunities	Provide your contact information when requested in patient satisfaction surveys.
	Volunteer to participate in research, for example, complete a research survey or take part in a focus group.
	Join committees relating to services you use or organizations you work with. For example: your hospital's patient advocacy committee; the parent-teacher association at your child's school; the workplace safety committee at your job.
Keep trying and watch for new opportunities	Opportunities are more likely to come along the more you build your advocacy skills and research connections.
	Strategies that do not work now might work if you try them again later, because community and researcher partnerships are becoming more common.

practices, and programs ensure that each person has what they need to live full, healthy lives. Recognizing that concepts like "equity" and "optimal" have different meanings in different contexts, research teams and their community partners should begin their time together by sharing definitions and aligning their objectives as to the outcomes to be achieved by working together.

Loper et al[4] emphasized the need to focus on engagement, connection, and trust in the families or communities that researchers wish to serve. Family and community engagement is described here as it integrates with the 5 phases of the LCIR framework: planning, design, implementation, evaluation, and translation.[5] This paper provides strategies for engagement across these 5 phases and describes how they build sequentially on each other. Partnering with families and communities focuses the intervention on outcomes that are meaningful to them and increases the potential for impact over the life course.

PLANNING PHASE

As researchers begin to consider studying a particular issue, a first essential step is for them to consider the limits imposed by their own identities, cultures, expertise, and professional lenses on the problem at hand. What is their experience in working with the population they seek to affect or the community where they wish to work? What is their willingness to accept that the way they view a problem, and its solution, may not be shared by the community? Are they willing to share some of their decision-making power with others? Are they ready to genuinely connect with a community that is new to them? In the planning phase, researchers should consider what terms are being used to describe the

problem at hand. To start this process, the Centers for Disease Control and Prevention provides a guide that identifies principles, terms to avoid, and preferred terms.[6] Language such as "vulnerable or marginalized groups" or "targeted population" should be avoided. Instead, it suggests using terms such as "population of focus," "under-resourced communities, or groups that have been marginalized." Language matters. Engaging representatives from communities will further help researchers identify respectful and culturally appropriate language that can be used in the proposal and implementation of the research. Researchers should also consider the education levels and titles used by members of the research team and understand the power dynamics at play when a research institution seeks to work in communities. Many universities have offices or departments that can support community engagement in research and offer resources that can be helpful. Researchers need to enter this work with an openness of mind and a willingness to hear and be changed by this engagement.

Conducting literature reviews of a research topic of interest is another important aspect of the planning phase. However, relying solely on data from studies with large sample sizes and substantial funding, which are favored by high-impact, peer-reviewed journals, risks overlooking work that elevates the voices and experiences of minoritized and under-researched populations. Much useful information and experience can be found in small-scale, qualitative research, and in gray literature, including reports, working papers, government documents, white papers, dissertations, and evaluations developed by organizations outside of the traditional academic space.

Community-focused review of academic and gray literature can help identify collaborators, raise up the experiences and perspectives of under-researched communities, and generate new ideas to consider. Referencing literature that considers the perspectives of communities often marginalized can aid in building the foundation to develop an effective intervention. It is also imperative to identify the gaps in the literature, especially concerning the strengths and needs of minoritized communities, and to design interventions to help address these gaps.

Ideally, researchers and their institutions will cultivate relationships with community leaders, a family advisory council, and community groups over time, and create time for conversations and learning about each other as people. This can later provide an advantage in responding to proposals because relationships and trust are already in place, the way everyone can contribute is known, and conversations about needed resources and time have been held. Shifting power and funding to community organizations is another way to support communities while also receiving authentic and honest input that informs research activities.

LCIR is characterized by an ongoing focus on long-term goals,[5] not just aims or objectives, which may present cognitive or logistical challenges for some researchers. Too often, research projects start in response to the announcement of a funding opportunity. When that opportunity demands a community partner, researchers rush to find a partner and to get a letter of support. This hurried process is unlikely to lead to research that will serve the community. In the ideal community-engaged process, researchers have identified a perceived need before they seek out funds. This approach offers an

important opportunity for researchers to take the time to listen to community groups and families to identify if the need is true and the solution appropriate. If not, this allows for a chance to begin working together to identify the right research question and response. Because research funding is not always structured to support this approach, researchers must take the long view in planning what funding opportunities to pursue at what time and how each funded project contributes to the infrastructure of their community engagement and their understanding of what research topics are most important to pursue from the community perspective.

DESIGN PHASE

Planning grants, which may last up to 6 months or more, provide an opportunity to develop a study in authentic collaboration with families and community partners. Such grants are rare as funders are reluctant to imply that implementation grants will follow. Some funders, such as the Patient-Centered Outcomes Research Institute, specifically fund engagement awards that help patients and families drive research questions and designs.[7] Others may provide support for several months of listening to and convening families and partners. When possible, researchers should explicitly build in planning and design time when writing proposals and include budget and methods flexibility within a framework of collaborative decision-making. While this can be a challenge as research study budgets are generally designed toward certain methods, it is possible to create a budget and process that allows for different options within the requirements of the funding.

When considering the design of your research study, it is important to consider the paradigm of inquiry that you will use to carry out your intervention research.[8] Historically, the predominant paradigm of inquiry in research uses a methodology that seeks to test hypotheses in controlled environments with an aim of understanding the effectiveness of an intervention to address a problem at a particular period within the life course.[8] This approach often leaves out the voices of those with lived experience, as the underlying assumption of this approach is that there is 1 truth or 1 answer to a particular hypothesis, regardless of who is involved in the study. In other words, an intervention either works or it does not work. Consequently, when developing life course research, it is important to use a paradigm of inquiry, such as critical theory, constructivist, or participatory,[8] which ensures the cocreation of concepts and interventions between researchers and research participants. These approaches can be done with quantitative, qualitative, and mixed methods research designs that address research questions that are jointly agreed upon by researchers and those whose lives are the subject of the study.

Various research designs can be used to develop an intervention that meets the needs of the community. Quantitative research can provide statistical information, often from larger samples, to confirm a hypothesis regarding the impact of an intervention intended to solve a preidentified problem.[9] However, quantitative research on its own easily lends itself to "detachment research,"[10] which separates the researcher from the participants in the absence of engagement with communities to decide what

questions are asked and who is asked. Qualitative research can be especially valuable in the field of life course intervention development as it can help to provide meaning, develop theory, understand a phenomenon, or define a problem or solution based on direct observation or input from the participants.[11] Qualitative research uses data collection methods, such as interviews and observations, that allow researchers to actively and fully engage with participants. However, qualitative studies have smaller sample sizes that can render the findings nongeneralizable beyond the community represented by research participants. Mixed methods can allow researchers to pull together the best of quantitative and qualitative research designs to understand and address the needs of the communities of focus.

Whether qualitative, quantitative, or mixed method approaches are used, it is important to engage communities of focus in all aspects of the research, including planning, design, implementation, evaluation, and translation. When thinking about developing an intervention study, it is important to understand that the main difference between an idea that starts out at a scientific conference and an idea that starts out scribbled on a flip chart in a community center or church sanctuary, is who is sitting at the table when the idea is generated. Bringing family and community members with lived experience to the table provides the opportunity for meaningful participation in the process of conceptualizing research questions and thinking about mechanisms for intervention. Researchers should use layered or multimodal approaches, such as a combination of key informant interviews, focus groups, listening sessions, and family research partners, to engage different

segments of the community of focus and seek to maintain active participation by these groups throughout the project. Furthermore, it is imperative that researchers regularly and formally provide feedback so that community partners know how their input is incorporated into the research process. Such respectful feedback will contribute to robust, continued engagement by family and community partners. Meaningful participation by individuals from the community involves the provision of their expertise as well as their time and energy. This merits equitable compensation for their contributions.[12,13]

One key consideration in the design of an intervention study is determining where the research will take place, as that can influence budget, participation, and the balance of power between the investigators and the participants. For example, conducting a study using a virtual platform, such as Zoom, rather than in-person at an academic institution may facilitate participation by families by eliminating the need for transportation and childcare, while simultaneously adding barriers of technology access and knowledge. Discussing the relative advantages and disadvantages of such solutions with families enhances the study's design and effectiveness by allowing the researcher to make the choices that work best in their research context while anticipating and preparing for any issues that might exclude potential study participants.

An additional consideration in the design phase is identifying collaborators who will assist in implementing the study. This may include community-based organizations that directly serve the needs of the focus population, individuals who can provide lived experienced insights, community-based support providers, and other stakeholders with meaningful interactions with the population identified for the study or intervention. The best approach is to engage family and community collaborators at the beginning when first developing the research study, so that they can inform the problem statement, research question, and best approaches to engage research participants. When drafting surveys, community partners can help determine what is asked and ensure that questions are relevant to the population being studied. When study materials, such as interview guides or surveys, are submitted to the institutional review board, they are likely to be more favorably reviewed if researchers can demonstrate that the content is acceptable to community partners. In not taking this approach, those conducting research may encounter a multitude of hurdles that delay the implementation phase.

IMPLEMENTATION PHASE

Implementing an intervention within the context of a research study is a complex process that balances the needs and expectations of several partners and usually requires compromises from all parties. When a study was designed and initiated as a collaborative process with members of the focus population, its implementation is likely to be easier and more successful. Community engagement in the design phase can facilitate recruitment, retention, and cooperation of study participants and ensure an adequate sample size.

A continuing role of community partners, especially community organizations, throughout the implementation phase is essential. This can be challenging due to "institutional policies and procedures" and "varying fiscal processes" of the research institution as well as the community organizations.[14] The continuing involvement of the latter and their specific roles and obligations should be spelled out formally, especially as compensation may be required. The research institution may have to anticipate and respond to some administrative limitations of small organizations. For example, they may not have the cash flow to cover participant incentives or expenses. Community partners should not be put in the position of being asked to do work before they have a contract or before agreed upon remuneration is available.

One study by Skinner et al[13] exploring the perceptions related to stakeholders and compensation found that "a majority of community stakeholders perceived funds to be 'rarely' (29%) or 'occasionally' (34%) fairly distributed between community and academic partners." Additionally, of those compensated, only 40% perceived the compensation to be appropriate for their involvement and contribution. Skinner also goes on to identify that "appropriate compensation was associated with both trust of research and the community being valued by researchers."[13]

Universities receive very high indirect funds from federal grants, but community organizations who are not often able to negotiate rates generally receive far lower levels of indirect funding. Research institutions can create "Community-Academic Partnerships" (CAP) to help streamline the process and reduce barriers to establishing equitable partnerships.[15] CAPs can establish budgetary guidelines that address "opportunity cost, the value forgone by not doing the next best activity … the cost of time and energy put into partnership activities instead of other valued activities" and overall expertise being provided to the research[16]

and thus, ensure equitable compensation of partners and participants. CAPs designed in collaboration with community partners are more likely to support the process of incorporation of stakeholders appropriately and effectively throughout the implementation phase.

Insights from partners can also enhance the quality of the data collection process. For example, community partners may make suggestions as to the best places to hold focus groups or other listening sessions, places familiar to and comfortable for community members. One study working with an indigenous community in northwest Alaska allotted funds for the travel cost for the researchers to spend time in this frontier community, which demonstrated that they valued the community they were working with and were willing to be on site to listen and learn.[16] Basing research activities in nontraditional settings recommended by the community can also be helpful. Hosting a listening session with a focus population of African American men might be better attended if it was held in a local barbershop rather than a meeting room at a local university. The participants could be compensated with a free haircut, and the barbershop owner could be compensated for the time the shop was reserved and for the cost of the cuts. The traditional means of signing up participants for the study session could be used, along with the other logistics involved with hosting a listening session. Everyone involved would benefit from such a local and collaborative process.

Being responsive to partnership input can significantly contribute to the success of implementation activities. Good quality research requires a certain rigor, yet circumstances change, and the

implementation process needs to be adaptable. Researchers working with community partners who have been involved from the start and who are consistently engaged and informed, are more likely to understand that alterations in the study are necessary and will be supportive of those changes. Being transparent and responsive will build trust in the partners and the process. Once established, this trust creates empathy, and empathy can help manage challenges inherent in intervention research.

EVALUATION PHASE

Evaluation of the engagement process is an integral part of participatory intervention research. Near-continuous evaluation is characteristic of the most successful partnerships, with variants of the question, "Is this working for you?" repeated regularly. In family and community engagement, the act of evaluation has social and symbolic implications as well as functional ones. Engagement evaluation that is transparent, flexible, and accountable proactively addresses concerns that research may be paternalistic, rigid, and perhaps even exploitative. Asking people to complete short anonymous surveys after meetings, for example, can help the full team understand if people are feeling heard, seen, and respected. Creating opportunities to evaluate in an ongoing fashion during the project makes it possible to address concerns and celebrate successes along the way, leading to stronger partnerships.

The Family Engagement Framework and the related Family Engagement in Systems Assessment Tools, designed by Family Voices for use by organizations, provide a compendium of resources that are readily applicable to researcher

undertakings to ensure meaningful family engagement in their work.[17] The framework identifies 4 domains (commitment, transparency, representation, and impact) and 20 items that support authentic family and community engagement. When applied to intervention research, the framework offers a helpful roadmap for recognizing and creating authentic family engagement, which can advance equity.

The Family Engagement in Systems Assessment Tools are a self-assessment tool built around the following 4 domains: (1) the importance of compensating family and community partners and having a family engagement policy and champion (commitment); (2) ensuring family and community partners have a clear understanding of their role and support for it (transparency); (3) recruiting participants who are representative of the population to be served (representation), and (4) identifying the contributions that family and community partners make to research (impact).[18]

To promote family and community partnerships in LCIR, the process and nature of family and community engagement should be included by researchers when they publish their work.[19,20] This recommendation is not intended to make family and community engagement the central feature of the work, nor would it elevate evaluation activities to the extent that they require Institutional Review Board approval. However, it would signal to other researchers that such engagement is an important aspect of this type of research and allow them to assess the quality and extent of engagement underlying published research findings. The updated Guidance for Reporting

Involvement of Patients and the Public includes both a long form and a short form to assist researchers to engage effectively with families and communities. The Guidance for Reporting Involvement of Patients and the Public long form is used for research on family and community engagement as a topic, while the short form is for research that uses family and community engagement as a tool.[19]

TRANSLATION PHASE

Translation of research is intended to both inform the population of its findings and introduce improved approaches into practice. Research findings might be best presented in a format where discussion between researchers and the families and the community is emphasized. This gives opportunity for feedback and community-centered dissemination strategies. LCIR seeks to examine how and when to most effectively intervene in the life course to optimize health development trajectories and outcomes. It considers the well-being of the whole person in the context of their family and community, identifying strategic points to intervene to reduce risk and maximize protective factors.[21] The results of LCIR are often used to impact public health and public policy for longer-term change. Insights as to how best to have this impact can be provided by community members who participated and will be affected. Without thoughtful, collaborative consideration of the implications of the research for public health and policy, there may be unintended consequences to its translation. Community members are best positioned to understand the current and historical social contexts that may affect the interpretation of the research findings and its implications. These perspectives are valuable, especially

when achieving health equity is the goal. Community input can build on the significant work that has been done to shift from focusing on the behaviors and outcomes of individuals from racial groups that have been marginalized to "a broad, systemic view that situates these inequalities within the social, economic, and political structures of societies that maintain the dominance of a single racial group."[22]

Recognizing and employing multiple ways of knowing where and when the community "voices and epistemologies" are at the "center of the research process" brings balance to the usual power dynamics underlying typical academic research.[23] Such knowledge strengthens the effectiveness of translating and disseminating findings to have the greatest acceptance and impact. There is value to paying close attention to the process and outcomes of seeking community partner guidance on interpretations of research.

CONCLUSIONS

The LCIRN is focused on developing and promoting transformational change to improve health outcomes across the life span. Family-professional partnerships, cultural competency, clear and transparent communication, and community collaboration are central to effective life course research. Engaging the populations of focus throughout the process of such research, from planning through design, implementation, evaluation, and translation, is essential. A holistic perspective on health over the life course and approach to family and community partnerships will be reflected in research findings with broad practical applicability and strong translational potential.

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